

Is There a Duty to Die in Europe? If Not Now, When?

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I believe that we have invented a new kind of death in the last 60 years or so. I think this new kind of death makes a profound difference – ethically, legally, socially, theologically and philosophically. I have spent the last part of my career pondering the implications of this new death. I am notorious for an article I published some 15 years ago entitled “Is There a Duty to Die?”¹ I argued that there is.

I think there has been a duty to die for millennia. But within wealthier societies in more recent times, it has usually been quite rare, requiring very unusual circumstances. One thinks of a captured secret agent who is afraid that under torture she will give up too much information, or of Captain Oates, a member of Scott’s expedition to the South Pole, who walked out into a raging blizzard when he became too ill to continue. Both commit suicide and arguably both may have had a duty to do so. However, I believe that our new kind of death makes – or will soon make – a duty to die much more common. I think there is a fairly good chance that I will one day face a duty to die. If I do, I hope that I will be able to end my life as I have tried to live it – responsibly, and both loyal to and considerate of my loved ones.

My earlier essay is, however, very contextual. It presupposes the context of the contemporary United States and the U.S. healthcare system. I do not know enough about European healthcare systems to know whether the argument of that paper is generalizable to European contexts, though I suspect that much of it is. In the present paper, after presenting my argument in favor of a duty to die, I offer some factors that strike me as probably applicable across advanced healthcare systems, either now or in the very near future. But that will be as far as I can take the argument. I must leave it to those more familiar with healthcare systems in Europe to determine whether there is a duty to die in Belgium, in France, in Germany, etc.

Introduction: The Ethics of Contexts and Ethics within a Context

I will be considering personal responsibility for individual choices, not the design or reform of healthcare systems. Individual choices always presuppose a context and

personal responsibility varies with the context. People who think about how to make healthcare systems ethically better are thinking about what I have called *the ethics of contexts*. Making changes in a healthcare system changes the contexts in which people make decisions and this often changes the responsibilities that individuals covered by that healthcare system have. Thinking about an optimally just healthcare system is an important endeavor, obviously, and the responsibilities people would face within such a system is one small piece of that enterprise.

But here I want us to consider our individual responsibilities as we face the end of our lives *in our given context*. As an agent, the context is a given for me; there is little I can do to change that context within the timeframe in which I must act. So I must make my moral decisions within that context. Granted, the context *itself* may be grossly unethical. I believe that many elements of the healthcare system in the United States *are* unethical. But I cannot normally free myself from my responsibilities by protesting: “this entire context is unethical – I shouldn’t be in this situation in the first place.” That may well be true, but it is irrelevant because I do find myself in this situation and my responsibilities are defined, in part, by it.

The fact that I am focusing on personal responsibility means that I am not talking about a social policy of any kind, certainly not a policy of involuntary euthanasia. My argument also cannot be used to support a duty to die on the part of the demented, the mentally handicapped or children. Those who are not competent adults are not capable of having a duty to die. I might mention in passing, however, that I support policies that permit advance directives requesting euthanasia. That, on my view, could be an attempt by a competent adult to ensure that his life will end responsibly, even if he becomes incompetent to make decisions for himself.

Two further points of clarification: First, I restrict the scope of my argument to the elderly. As Daniel Callahan has pointed out, the death of a 27 or 33-year old is tragic in the way that the death of an 82 or 87-year old is not.² Although a 27 or 33-year old can also have a duty to die, such cases are much less common, much more troubling and require more by way of justification. Second, I used the expression “duty to die” because Richard Lamm, a former governor of the U.S. State of Colorado, was once quoted as saying that old people have a duty to die and get out of the way.³ That remark was widely publicized. Without thinking the implications through carefully enough, I simply repeated the governor’s expression because it had currency. I will continue to use that expression here. But a “responsibility to die” would be a better expression – I do not think that anyone has a moral right that would be violated if I failed to live up to my duty to die. “Responsibility” is also just a better word, rooted as it is in the verb, “to respond.” Ethics, on my view, is more about responding thoughtfully and caringly to situations than it is about following abstract rules of conduct.

I am trying to think about how to face the end of my life responsibly and a responsible ending may, I believe, include making sure that I do not live too long. A duty to die is based on harms I will impose on my loved ones if I continue to live. My argument, then, is about personal ethics, about moral responsibility within a situation or context. In the terms of my argument, the duty to die is a very intimate responsibility,

grounded in the responsibility to try to shelter one's family and loved ones from great burdens.

II. Our New Kind of Death

When I was a boy, I was afraid of death. And the deaths I feared had three characteristic features: I was afraid that death it would be unexpected, that it would be quick and that it would come too soon. Death might hit me "completely out of the blue" and it could even "all be over in the blink of an eye." I will call deaths of these kinds "traditional death." This is the death that has traditionally fueled both popular imagination and theoretical reflection. There are many tales, parables and prayers about this kind of death.

Throughout history, when people died of infectious diseases, of accidents, in war or in childbirth, this is the kind of death one usually got. These deaths were not often predictable. And, though there have always been exceptions (e.g., tuberculosis), one's terminal illness usually lasted a few days or weeks at most, from onset to death, or at least to delirious non-comprehension. The fear then was that death would come as an interruption: one's life could be cut off without warning, leaving potentialities unrealized, plans half-finished, dreams unfulfilled and young children orphaned. The fear of being bedridden for years and years did not loom large then – someone who was bedridden for any length of time usually caught a pneumonia and pneumonias could not be treated, they died.

Just a little over one hundred years ago, Sir William Osler, sometimes referred to as the father of modern medicine, said that pneumonia is "the friend of the aged."⁴ In the U.S., it was popularly known as "the old man's friend." But we have killed the old man's friend, primarily since World War II.⁵ Physicians tell me that it is largely antibiotics and the respirator that have wrought the change from traditional death to our new kind of death.

Our new kind of death is, then, the result of the *successes*, not the failures, of contemporary medicine and we are all glad to have that medicine. I certainly am. But like many other technological advances, our new kind of death leaves us facing tremendous ethical challenges. We are largely unprepared – morally, legally, theologically, philosophically and socially – for our new kind of death. Moreover, in terms of the evolution of a culture, World War II is very recent.

Of course, I may still get the traditional death – sudden and unexpected – I feared as a young boy. But the odds are against it. Perhaps more importantly, I can no longer reasonably fear a death that comes too soon. At 71, I am simply too old for that to be a reasonable fear. And death is now normally *far* from unexpected. A noted geriatrician and bioethicist, Joanne Lynn, once remarked that the average American now knows three years in advance what she or he will die of. And, Dr. Lynn went on to say that the average American male will be debilitated for 5 years before he dies; the average American female will be debilitated for 8 years before she dies.

Three, five, eight. Those are awe-inspiring numbers. We now live in the shadow of death for a very long time. And we should expect all of Dr. Lynn's numbers to be even larger by the time we come to the end of our lives. Better diagnostic tools will enable us to know earlier what we will die of; better treatments will permit us to live with terminal illnesses much longer. Consider just one example: We now have diagnostic tests that enable us to diagnose Alzheimer's years before any of the symptoms are observable. And it's not hard to imagine that someone will come up with a drug that would slow the progression of Alzheimer's by 50%. What a wonderful medicine that would be! But then, instead of dying of Alzheimer's over an 8-15 year period, we could live for 15 or 20 years with Alzheimer's and we could have known for 15 or 20 years before that that we would eventually get Alzheimer's.

The success of our life-prolonging medicine has brought with it a new fear, the fear that death will come too late. When I give talks about death and dying to non-academic audiences, I often start by explaining the traditional fear that death would come too soon. Then I ask, How many of you are afraid that death will come too *late*? Usually, about half of the audience raises their hands in public acknowledgement of this fear. Many of us now fear that death will come long after we have completed our life-plans, long after we know what to do with ourselves, long after we have lost all of our friends, long after we even are ourselves. (Between 40% and 60% of those over eighty have dementia.) Barring a sudden death or sudden incapacity from a massive stroke or some such, we will have to face very difficult decisions as we approach the end of our lives. We will need to strategize ways to avoid a death that comes too late. We may have to take very active steps if we are to avoid a death that comes too late.

III. Avoiding a death that comes too late – a good death and a responsible death

When death comes too soon, the tragedy is often, even usually, a double tragedy. Consider a 32-year old mother of two small children whose career is just beginning to blossom when she learns that she has a terminal cancer. Such a death is a tragedy both for the woman who is dying and also for her loved ones. We grieve both for her – for her uncompleted projects and plans, for the experiences she might have had, for what she might have become – and for her family and loved ones who must now go on without her. Her death is a tragedy for them, too – especially for her husband and her young children, but also for her parents and close friends.

Similarly, when death comes too late, the tragedy is also often double, a tragedy both for the one who is not yet dying and also for her family and loved ones. A death that comes too late is often tragically burdensome for the person who must endure (or *believes* she must endure) years of a debilitated existence and also for her close friends and family who must support her through these years when she is unable to care for herself.

My mother and one of her sisters both spent the last years of their lives sitting by the side of their beds in very nice nursing homes 3000 km from each other. Neither was mentally impaired, and neither suffered great pain or other physical discomforts, though my aunt was nearly blind. Both my mother and my aunt found such an existence

unbearable. My mother said over and over, “Why does this have to take so long? I’m ready to go – I’ve been ready to go for *years*. Why does this have to take so long?” The suffering of both of these women was exacerbated by the fact that neither had a terminal illness. Because they had no life-threatening illnesses, there was no end in sight. They had lived their lives, and both suffered from an overwhelming sense of uselessness and purposelessness. They were ready to die but death was nowhere in sight. I believe those years in a nursing home probably even cost my mother her life-long Christian faith.

In the cases of my mother and aunt, the burdens of a death that comes too late were largely confined to themselves. Both had outlived most of their friends and had lost contact with the others as infirmity decreased mobility, making distance an increasing challenge and finally, an insurmountable barrier. Their children were grown and had scattered across the U.S. Neither of these women’s families was unduly burdened by the responsibility of caring for them. The burdens of a death that came too late fell almost exclusively on themselves. I call the attempt to avoid the *individual* tragedy of a death that comes too late the *art* of dying and have written a little about it.⁶ Most of the generation that is dying now did not expect to have to strategize to ensure that their deaths would come soon enough and they were often unprepared to meet this challenge. My aunt eventually found her way out by refusing to eat and she was fortunate enough to be in a nursing home that supported her in that decision. My mother, however, was trapped by her religious upbringing. She had been raised to believe that ending your own life is “the worst thing you can do.” Her religion let her down at the end; it was inadequate to that challenge of a death that came too late.⁷

If the generation that is dying now is unprepared, my generation should not be. Most people my age carry searing family stories about a family member who died far too late. We know very well that the best death is not the one that can be put off longest and that the last years of life can go very badly if we stay alive too long. Nevertheless, the art of dying will be a very difficult art to develop and many of us will be pretty much on our own in trying to avoid such a death. Our ministers and doctors, our family and friends, are often unwilling to help us even *think* about avoiding a death that comes too late, much less providing help in activities to ensure that we die sooner rather than later. If we are planning to do something to end our lives, many of them would rather not know about it. Although I won’t see it, of course, it will be very interesting to see whether my generation has learned enough from our experiences of deaths that came too late to develop the art of dying at something much closer to the right time – neither too soon nor too late.

IV. Facing the End of Life Responsibly

I mention the *art* of dying mainly to distinguish it from the *ethics* of dying. The art of dying is primarily a matter of prudence and discernment; it is the skill of arranging for an end that is good for the person who is approaching the end of life. But our new kind of death also forces upon us troubling questions about ending life responsibly. When death came unpredictably and fairly quickly, there was little need for talk of responsibility. And a death that comes too soon is *morally* simpler, no matter how

emotionally and even spiritually difficult it may be. We take our loved one to the hospital and the doctors do what they can to avoid or postpone death. And when they can do no more, there is moral solace in knowing that we all did what we could. We grieve with the survivors and then we try to move on. But we move on without a burden of guilt or gnawing moral questions about whether we did the right thing.

Ethics at the end of life is, as I understand it, primarily other-directed. Those who are still in positions of power and public responsibility will have *many* others to consider as they approach death, but for most of us, ethics at the end of life needs to consider only the interests of family and close friends. The *ethics* of dying grows out of recognition that the lives of close friends and family are interwoven. Because the lives of others I care deeply for will be dramatically impacted by choices I make at the end of life, I ought not to make decisions based simply on what I want for myself. That would be irresponsible – inconsiderate and selfish in the extreme.

The search for a responsible ending focuses on the impact of our last years on our family and loved ones. When we can no longer take care of ourselves, our care must be provided or paid by someone, and our ongoing medical treatment must also be paid for by someone. If family caregiving is desired or sought or required, the rest of the family will need to make major adjustments in their lives to take care of us.

Perhaps I need to emphasize that I am not talking only or even primarily about *medical* resources. Even if I do not consume vast quantities of medical resources at the end of my life, I will likely consume vast family caregiving resources. The care I require could easily overwhelm the “caring capacity” of my partner or my sons’ families, forcing them to neglect or give short-shrift to their other responsibilities and to neglect care for themselves.

A literature is beginning to accumulate about the effects of long-term caregiving on family caregivers.

- The famous SUPPORT study was one of the first to document lifestyle changes and burdens of end-of-life care in the U.S.⁸ The SUPPORT study included only patients whose APACHE score predicted they had less than six months to live. When these patients survived their initial hospitalization and were discharged back home, the study found:
 - 1/3 required considerable family caregiving
 - In 20% of these families, one family member quit work or made some other major lifestyle change (e.g., relocate to a different city)
 - 1/3 of these families lost all of their savings
 - 30% of these families lost a major source of income.
- There is now a burgeoning literature on the burdens of family caregiving. Careers are lost and savings wiped out by caregiving, of course. When caregiving becomes extensive – and many elderly persons eventually require care 24 hours/day, 7 days/week – family caregivers usually become depressed. They lose hope. Their friendships vanish because there is no longer time for

them. They suffer physical injuries from the physical requirements of caregiving. They start neglecting their own health (e.g., no longer make or keep appointments with their own physicians) and their health declines. Health outcomes are worse for family caregivers who must provide more than a small amount of caregiving.

- Caregiving may even have mortal consequences. The most dramatic finding I am aware of comes from a study that compared 80-year olds who were caregivers for their spouses with 80-year olds who were not. In addition to age, health, economic status, sex, education and other stressful life events were controlled for. At the end of the 4½ year study, the caregivers who reported that caregiving was stressful were 63% more likely to have died than the non-caregivers.⁹ And this study is likely to have *underestimated* the risk of mortality for a number of reasons.¹⁰ Caregiving is an independent risk for mortality. I might unintentionally kill my wife just by trying to prolong my life. How could I do that to her?

V. *The argument for a duty to die*

My argument for a duty to die is simple:

1. Many medical treatment decisions have a dramatic impact not only on the life of the patient, but also on the lives of the patient's family and loved ones. When family must provide care for a chronically-ill, debilitated or demented elderly family member (either through purchasing it or by delivering it), the lives of all are usually affected in important and long-lasting ways.
2. Therefore, a patient-centered bioethics must be abandoned. A *patient-centered* bioethics makes treatment decisions by asking, What does the patient want? or What is best for the patient? But there is no good reason for ignoring the legitimate interests of other family members whose lives will also be affected by medical treatment decisions. Medical treatment decisions, like all major decisions within a family, should be made by considering what is best for all concerned.
3. Although families have a responsibility to care for chronically ill or debilitated elderly family members, the elderly also have responsibilities to their loved ones. These include the responsibility to try to protect the well-being of their families. In sickness as in health, it is often wrong for a family member to choose what she wants for herself or what is best for her.
4. There are some burdens that are too great to legitimately expect, ask, or even allow others in one's family to bear.
5. In many cases, there is no way to continue to live without requiring one's family members to bear such burdens.
6. In such cases, one still has a duty to try to protect one's family from those burdens.

7. This duty can include the duty to refuse life-prolonging medical treatment. But it can also include the duty to end one's life in the absence of any terminal illness at all.

This seems clear and obvious to me. But some points in this argument may be worth emphasizing: I am not denying that family members and close friends of a debilitated or ill elderly person have a duty both to care and to provide for an elderly relative. My claim is that this responsibility is not unlimited and that family responsibility at the end of life is a two-way street: the debilitated elderly family member also has responsibilities to his family. Family responsibility for a debilitated elderly family member cannot be unlimited because it must be weighed against other responsibilities in a family caregiver's life and even against a family caregiver's completely legitimate claim to a life of her own – a claim to her own autonomy, to friendships and other sources of happiness, and even to some rest and recreation. (Incidentally, most studies have found that respite care is not sufficient to significantly alleviate the burdens of family caregiving.¹¹⁾)

If we choose to do our ethical thinking in terms of rights, my claim is that the rest of the family also has rights and that they are not automatically trumped or invalidated by the needs of a debilitated or chronically-ill elderly family member. Put in terms of family and friends helping each other bear life's burdens, ethics at the end of life is not simply a matter of calculating what is best for an elderly family member. That kind of moral calculus would implicitly reduce the rest of the family to means to her ends.

Finally, absent mental illness or senility, chronic illness or debility does not obliterate moral agency. When I become old and feeble, I will still have responsibilities, including some that grow out of my increasing incapacity, including perhaps the loss of the ability to take care of my basic everyday needs. The view that the elderly still have serious moral responsibilities is, I submit, part of affirming their dignity. For Kant, at least, human dignity grows out of the capacity for moral responsibility. If there is anything importantly correct about that view, it is an assault on the dignity of the elderly to claim that the chronic illnesses or physical disabilities most of us will encounter at the end of life remove all significant moral responsibilities from us.

This is one of the silver linings that comes with what may be a weighty moral responsibility to end my life: I am still a moral agent, capable of important decisions and actions; I am still part of a moral community, connected to others, to family and loved ones. This connection is itself a silver lining, I believe, and it is capable of endowing the end of life with meaning. At the end of life, we *must* see ourselves as connected to something valuable that will outlast us, on pain of complete meaninglessness. But that is the story for another occasion.

VI. A Case Involving Issues of Justice Within the Family

I offer one more consideration in support of a duty to die: death is neither the greatest evil nor the greatest burden. In fact, viewed from an "over-a-lifetime perspective" rather than a "slice of time perspective,"¹² the burdens to family members of providing

care for a patient can easily be far greater than the burdens to the patient of foregoing this care. Consider the following case, a case with which I was familiar:

An 87-year-old woman was dying of congestive heart failure. Her APACHE score predicted that she had less than a 50 percent chance to live for another six months. She was lucid, assertive, and terrified of death. She very much wanted to live and kept opting for rehospitalization and the most aggressive life-prolonging treatment available. That treatment successfully prolonged her life (though with increasing debility) for nearly two years. Her 55-year-old daughter was her only remaining family, her sole caregiver, and the main source of her financial support. The daughter duly cared for her mother. But before her mother died, her illness had cost the daughter all of her savings, her home, her job, and her career.

Consider which is the greater burden, the burden would you more hope to avoid:

- a) To lose a 50 percent chance of six more months of life at age 87?
- b) To lose all your savings, your home, your job and your career at age 55?

To most people, the answer is very clear: b) is the burden one hopes most to be able to avoid. And with reason: Lost savings cannot be recouped starting at age 55. New careers are also difficult to establish then; indeed, it is difficult for many to even find a financially comparable job at that age. Home loans are almost impossible to arrange at that age, especially with no savings. So, the rest of the daughter's life will be significantly affected by her mother's decisions about her healthcare. My argument in favor of a duty to die might, then, also be cast in terms of justice within the family. At least this: on most people's assessment, the mother's decisions impose greater burdens on her daughter to avoid lesser burdens for herself. When we consider questions of justice and health care, it is morally myopic to overlook fairness to family caregivers.

VII. Deciding Who Has a Duty to Die

For those who have followed me this far, there is a very weighty problem of moral judgment: Who has a duty to die? And when? There will not, I think, be simple, universally-applicable answers to such questions. Answers will have to be very particular and individualized . . . to the person, to the situation of her family, to the relationships within the family, etc. But that having been said, I offer the following considerations:¹³

1. There is more likely to be a duty to die when prolonging your life will impose greater burdens -- emotional burdens, extensive caregiving, disruption of life plans, and financial hardship -- on your family and loved ones. This is the fundamental insight underlying a duty to die.

1.1 In determining what is "too much of a burden," an "over-a-lifetime perspective" rather than a "slice of time perspective" is appropriate

2. A duty to die is more likely if your loved ones' lives have already been difficult or impoverished (not just financially) -- if they have had only a small share of the good things that life has to offer (especially if through no fault of their own).

3. There is more likely to be a duty to die to the extent that your loved ones have already made great contributions -- perhaps even sacrifices -- to make your life a good one. Especially if you have not made similar sacrifices for their well-being or for the well-being of other members of your family.
4. A duty to die is more likely to the extent that you have already lived a full and rich life. You have already had a full share of the good things life offers.
5. Even if one has not lived a full and rich life, there is more likely to be a duty to die as one grows older. As we age, we give up less by giving up our lives, if only because we will sacrifice fewer years of life and a smaller portion of our life plans.
6. To the extent that you can make a good adjustment to illness or handicapping condition, there is less likely to be a duty to die. A good adjustment means that less sacrifice will be required of loved ones and there is more compensating interaction for them. (Still, we must also recognize that some diseases -- Alzheimer's or Huntington's chorea -- will eventually take their toll on our loved ones no matter how courageously, resolutely, even cheerfully we might manage to face that illness.)
7. There is less likely to be a duty to die if you can still make significant contributions to others, especially to members of your family. The burdens to family members are not only or even primarily financial, neither are contributions to them. However, the old and those who have terminal illnesses must bear in mind that the loss their family and loved ones will feel when they die cannot be avoided, only postponed.
8. There is more likely to be a duty to die to the extent that the part of you that is loved will soon be gone or seriously compromised. There is also more duty to die when you are no longer capable of giving love. Part of the horror of Alzheimer's or Huntington's, again, is that it destroys the person we loved, leaving a stranger and eventually only a shell behind. By contrast, someone can be seriously debilitated and yet clearly still be the person we love.
9. There is more likely to be a duty to die to the extent that you have lived a relatively lavish lifestyle instead of saving for illness or old age.
10. Greater ties of deep affection and loyalty increase the likelihood of a duty to die. As far as my present argument goes, there is no duty to die for anyone who is all alone at the end of life. But perhaps somewhat paradoxically, there is a greater duty to die for those who have families bound together by deep ties of affection, loyalty to each other and/or a strong sense of familial responsibility. If I outlive my partner, and I knew my sons had no concern about what happens to me and would not try to help me at the end of my life, I would no longer have to consider how to die responsibly. There would then be no one whose life would be significantly impacted by how I lived or died.

VIII. Factors that Might Increase the Duty to Die in Europe

Finally, we come to the question of whether any of this is applicable in European contexts. Different healthcare and social welfare systems bring with them different personal responsibilities. To some extent, the citizens of all democracies face decisions about how much social insurance to provide against life's misfortunes and whether to discharge collectively or individually our responsibilities to provide for the needs of the less fortunate. We must be careful here, however: the less fortunate may not be the debilitated elderly. As we have seen, they may be the *family* of the elderly.

The culture of the United States has always had a strong individualistic streak and it seems that we are now moving toward an even greater emphasis on individual responsibility. Americans aren't much on solidarity. By contrast, most European countries support a much stronger social safety net. If I am correct, the American healthcare, welfare and retirement systems make a duty to die much more common today in the U.S. than it is in most Western European countries. That is one of the generally unnoticed features of a commitment to individual responsibility. With a weaker social safety net, the burdens of old age fall much more unevenly and heavily on some individuals and families than on others.

I believe a duty to die emerged earlier in the U.S. due to our individualistic culture, our fascination with high-tech medicine, and the quirks and defects of our healthcare system. But the data suggest that European countries will soon face the kinds of healthcare cost problems that prevail in the U.S. today: Though most European countries spend a far smaller percentage of their GDP on healthcare (and get better health outcomes for their expenditures), I do not think there is *any* highly-developed country in which healthcare does not consume an increasing percentage of GDP. Thus, the problem of increasingly expensive healthcare is not limited to the U.S. nor is it due entirely to the failures of the American healthcare system. Obviously, no country can devote an increasing percentage of its GDP to healthcare indefinitely.

So I doubt that a fairly widespread duty to die is due solely to the peculiarities of the United States and its healthcare system. But the question in most European contexts is not so much whether a duty to die is common right now. Rather, it is whether the healthcare and pension systems now in place can be sustained at a level that would prevent a fairly common duty to die from arising in Europe, as well.

I conclude this paper by listing four factors that have increased the duty to die in the United States. I think most are generalizable to other advanced healthcare systems. If not yet, then quite soon, I would think.

1. *Our new kind of death.*

Our new kind of death, wrought by medical progress and better public health, is the primary cause of a fairly widespread duty to die. Elderly people who are debilitated or who suffer from chronic illnesses for many years prior to death need a lot of personal care. Often, too, there will also be frequent hospitalizations for intensive treatment to deal with health crises, followed by discharge and a period of increased dependency after discharge. Although such individuals may face difficult moral decisions resulting

from their fragility and incapacity, we are the lucky ones. Those less fortunate died much earlier.

This new kind of death is, of course, prevalent not only in the United States; it is found throughout Europe. I think it will pose increasingly difficult problems for the allocation of resources. Although I am more concerned here with family resources than a country's resources, all countries' pooled healthcare resources will be strained by the new death. I expect our new kind of old age and dying will make the duty to die much more common throughout Europe. We can no longer pursue a healthcare system that is dedicated to prolonging life as long as we can do so, provided only that the patient wants the life-prolonging treatment. That is or soon will be unaffordable.¹⁴ We simply have to ration healthcare.

The problem of our new kind of death is exacerbated in many European countries by an aging population created by longer life expectancies and a declining birthrate. The combination of these two demographic factors results in a much smaller number of working people who must support the social safety net for the elderly. A United Nations report issued in 2009 estimated that "by 2050, the number of persons in the working ages per older person is projected to be . . . 2.2 in the more developed regions [of the world], implying a decrease of 48% relative to 2009."¹⁵

2. We have the ability to invent new life-prolonging medical technologies faster than we can grow the economy to pay for them.

Ongoing medical progress is a related cause of an increasingly frequent duty to die. I believe that medical science can keep on discovering or inventing new and better treatments, treatments that will continue to be very attractive to people with chronic illnesses or simply degeneration due to aging. The new and better treatments will only rarely be less expensive than the older treatments they replace. Moreover, I think medical science will continue to be able to invent/discover new treatments much faster than we can grow our economies to pay for them.¹⁶

This, I think, will prove to be true for any country's economy. Granted, many medications and treatments are developed primarily as attempts to capture a share of a profitable market or to extend the patent life and profitability of existing treatments. But putting those aside, I expect developments that do represent better healthcare and that are genuinely desired by the patients with the relevant illnesses or conditions to outstrip our ability to pay for them.

On the other hand, a duty to die could probably be *decreased* by government or private insurer decisions not to pay for these new treatments or to ration them by age. If we stop paying for improved medical technologies and treatments, or to limit the population in which these new developments will be used, there will be less incentive to develop them. Or, better treatments will still be on the market, but not available for those participating in a given insurance plan.

An age-based system of rationing healthcare would probably result in fewer elderly people living with chronic illnesses or in a debilitated state. I would support age-based rationing for reasons carefully developed by Norman Daniels¹⁷ and Daniel Callahan,¹⁸ among others. It is worth noting that age-based rationing would probably *decrease* the number of people facing a duty to die. But this “relief” from a duty to die would come at the expense of an earlier death for many elderly persons.

In the United States, all of these measures to stem the tide of medical progress would be extremely difficult or impossible even to discuss publicly, much less to enact. Tremendous social pressure to make new treatments available to desperate patients is generated even before these treatments have been proven successful. (The internet has contributed in a major way to this development by making it much easier for patients to find out what new treatments have been developed and also by making it much easier to organize advocacy groups for patients with specific illnesses.) Hopefully, European countries will be able to have a more reasoned and realistic discussion about the need to limit healthcare expenditures and the justice of age-based rationing of scarce healthcare resources.

3. *The Ethics of Patient Autonomy and Patient Responsibility*

Perhaps the emphasis on patient autonomy in American bioethics is also symptomatic of our individualistic culture. In any case, bioethicists in the U.S. have argued quite successfully against physician paternalism and also an ethics based on a *telos* supplied by medicine or medical science. The argument, in brief, went like this: all medical treatment decisions presuppose value judgments and the values guiding a choice among the available alternatives should be the patient’s values, not the professional aims of medicine or the goals of medical science. “It’s her body; it’s her life, so she should choose what will be done to her.” Most American doctors have by now absorbed this ethic of patient autonomy.

But bioethicists, physicians and patients seem not to have noticed that responsibility comes with autonomy and the right to control your own medical treatment. Probably we are all more receptive to the idea that we have the right to choose than we are to the responsibilities that come with our choices. But the power to choose is always accompanied by responsibility. So, the doctrine of patient autonomy has the unintended consequence of saddling seriously ill, frightened and debilitated people with very weighty moral responsibilities. Including, I believe, a duty to decline further life-prolonging treatments and to die as a result. However, the *responsibilities* of patients are routinely ignored in American hospitals; patients are very rarely encouraged to think about what their healthcare decisions will mean for their families and loved ones. This, too, places additional responsibility on the shoulders of patients – “If I don’t consider the well-being of my loved ones, no one is going to.”

Imagine, by contrast, a much more paternalistic medicine. To the extent that paternalism dominates healthcare, *physicians* and healthcare planners bear the moral responsibility for the healthcare we get. So, there are or could be healthcare systems in which doctors simply refuse even to offer treatments to elderly people when they know

such treatment would result in undue burdens on their families: “We shouldn’t hospitalize her and attempt to pull her through the present crisis because her family simply can’t afford it and the care she will require if she survives. Even if they might be able to afford it, they shouldn’t try. Caring for her would usurp too many other more important family goals.”

I have been told that many European healthcare systems are somewhat more like this. To an American ear, that kind of paternalism sounds outrageous: What could possibly justify my doctor – or worse, some bureaucrat – making decisions about what kind of healthcare I should get at the end of my life? But the point here is not whether this kind of paternalism is justified. The point is the simpler one that *IF* my doctor made such decisions as I approached the end of life, then *she*, not I, would bear the moral responsibility for the consequences of my healthcare for my family and loved ones. Her decision to limit my care in accord with what is best for my entire family would free me from the moral responsibility of considering that, provided that she had done a good job in assessing what’s best for my family. I would then be much less likely to have a duty to die; my doctor would have already have taken care of ensuring that death did not come too late for me.

4. “Outsourcing” more care to families.

In the United States, insurers, both public and private, have tried to reduce their costs by limiting the reimbursement to doctors and hospitals for care of their patients. Hospitals are increasingly paid a fixed sum for providing care for patients with a given diagnosis. The hospital benefits financially if it can provide care for a patient for less than that amount. Similar incentives for hospitals are, I believe, also in place in Europe. This is a good thing in that it encourages hospitals to be more efficient and to try to eliminate expensive but only marginally-beneficial treatments. But one of the ways in which American insurers and hospitals have reduced their costs is to “outsource” to unpaid family members a lot of care that they used to deliver. This phenomenon is known as “discharging quicker and sicker.” Obviously, the more involved and caring the family, the more care hospitals can require them to give – “this patient has a good support system” doctors and discharge planners often say. But families are not merely patient support systems and it is unethical to treat them as mere means to the interests of patients.

Caring families are assigned the task of providing not only routine nursing care, but increasingly-sophisticated treatments as well, including using wound vacuums, tending to Hickman catheters for IV antibiotics and feeding tubes, repacking wound dressings, and sometimes even caring for patients on ventilators. By contrast, patients with “bad” families – families the hospital staff does not trust – will remain in the hospital for much longer or be discharged to other healthcare institutions. Some families are not trusted to deliver needed care to patients, others are believed likely to steal the patient’s medications for their own use or for resale, etc.

Forcing families to provide more of the caregiving has major ethical downsides. I have already noted the financial, caregiving, and even health-related strains this

practice puts on patients' families. It is clearly unfair to "good" families. Loyal, caring families are required to deliver much more care than dysfunctional, callous or antagonistic families. There is also an important issue of gender justice (at least in the U.S.), because it is usually women who provide this uncompensated caregiving even if the elderly family member who needs the care is the husband's relative.

But even with all of these ethical negatives, we might still want our healthcare systems to do just this. For one thing, most people would rather be in their own homes when they are ill. For another, given adequate training, a loving family member may well provide better care than the more impersonal institutional staff. For both reasons, most patients would probably rather be sent home to be cared for by family members. But perhaps most relevant to a comparison of alternative healthcare systems is this: If, due to budget limitations, our healthcare systems are straining to provide state-of-the-art care for everyone covered by the system, we might want these systems to require families to provide as much care as they will provide, so as to use the available funding to cover medicines and treatments that families cannot provide.¹⁹ However, by pursuing policies that have the effect of burdening families with more long-term care of the elderly, a healthcare system increases the incidence of a duty to die of those covered by that system.

IX. Conclusion

These, then, are four factors that increase the likelihood that we will face a duty to die at the end of our lives. I believe that all are or soon will be applicable to varying degrees in European healthcare systems. If so, a duty to die will become much more common in Europe in the near future. I would expect many Europeans living today to face the issue of how to end their lives responsibly. A responsible ending will, for many, include a duty to die.

Institutional arrangements can, however, only increase or diminish the incidence of a duty to die. Institutional arrangements can never completely eliminate it. A duty to die is also shaped, as we have seen, by the history and the domestic "policies" of an individual family and thus can also be created at the intimate, personal level of one's own family. Those who have insisted "don't ever put me in a nursing home" have thereby increased the likelihood that they will face a duty to die.

So, even if long-term care is not being outsourced to families by the healthcare system under which one lives, one may have created a duty to die for oneself by insistence that nursing home care is unacceptable. Too much emphasis on the responsibility of children to care for their parents when they are old and frail could also create a duty to die on the individual level. Finally, institutional safety nets will never cover all of the difficulties that can befall families and loved ones. For these reasons, institutional provisions will never completely eliminate the necessity to face the end of one's life responsibly.

Nor should any society try to completely eliminate a duty to die – an attempt to do so would represent a horrible misallocation of resources. No healthcare system will

be able to meet all of the healthcare needs of all its citizens indefinitely into the future. An attempt to do so would warp the culture of that society unconscionably, shortchanging other needs like education, public safety, maintaining the infrastructure, supporting the arts, etc. A sane society will not sacrifice all other goods on the altar of providing the longest lives and best healthcare that is technically possible.

In sum, I expect many Europeans living today to face the issue of how to end their lives responsibly. A responsible ending will, for many, include a duty to die. If this sounds just horrible, I can only urge all of us to remember that the duty to die is just the other side of the better health and longer lives we have been privileged to receive.

NOTES

¹ John Hardwig, "Is There a Duty to Die?" *Hastings Center Report* 1997; 27(2): 34-42.

² Daniel Callahan, *Taming the Beloved Beast* Princeton University Press, 2009, 179-80.

³ *New York Times*, March 29, 1984.

⁴ Osler W. *Principles and Practice of Medicine Designed for the Use of Practitioners and Students of Medicine*. 3rd ed. New York, NY: D Appleton; 1898:109.

⁵ In fact, we have not quite killed the old man's friend - the combination of pneumonia and influenza is still the fourth leading cause of death among those 75 and older. See Yoshikawa TT. Geriatric infectious diseases: an emerging problem. *Journal of the American Geriatric Society* 1983;31:34-39.

⁶ John Hardwig, "Going to Meet Death – The Art of Dying in the 21st Century" *Hastings Center Report* 2009; 39(4): 37-45.

⁷ There are many versions of Christianity, of course, but my mother's case may not be unusual. A hospital chaplain I worked with maintains that none of the traditional religions is of any help to us in dying – they were, he claims, formulated to deal with deaths that are very different from those we now face.

⁸ Kenneth E. Covinsky et al., "The Impact of Serious Illness on Patients' Families" *JAMA* 1994; 272: 839-44.

⁹ Richard Schulz & Scott R. Beach, "Caregiving as a Risk Factor for Mortality," *JAMA* 1999; 282: 2215-19. But see also Stephanie L. Brown, et al. "Caregiving Behavior Is Associated With Decreased Mortality Risk," *Psychol Sci.* 2009; 20(4): 488–494. This study found a decreased risk of mortality for elderly spouses who were providing fewer than 14 hours/week of caregiving. These are, however, very modest caregiving requirements and the authors hypothesize that their findings might not apply to caregivers providing more intensive caregiving.

¹⁰ Janice K. Kiecolt-Glaser & Ronald Glaser, "Chronic Stress and Mortality Among Older Adults," *JAMA* 1999; 282: 2259-60.

¹¹ Shoenmakers B, Buntinx F, DeLepeleire J. 2010. "Supporting the dementia family caregiver: the effect of home care intervention on general well-being" *Aging & Mental Health*, Jan;14(1):44-56. Mason A, Weatherly H, Spilsbury K, Golder S, Arksey H, Adamson J, Drummond M. (2007). "The effectiveness and cost-effectiveness of respite for caregivers of frail older people" *Journal of the American Geriatric Society*, Feb;55(2):290-9.

¹² I borrow the terminology from: Robert M. Veatch, "Justice and the Economics of Terminal Illness" *Hastings Center Report* 1988; 18(4): 34-40.

¹³ This is, with only slight modifications, the list of considerations previously published in: John Hardwig, 1997.

¹⁴ The London School of Economics published a report about dementia in 2009 that stated, "There are currently 700,000 people in the UK with dementia. By 2021, the figure is expected to rise to 940,110, before reaching 1,735,087 in 2051." <http://www.disabled-world.com/health/aging/dementia/uk-dementia-statistics.php#ixzz1OydMf0R7>

¹⁵ World Population Ageing 2009, United Nations Department of Economic and Social Affairs/Population Division. http://www.un.org/esa/population/publications/WPA2009/WPA2009_WorkingPaper.pdf, 21.

¹⁶ An assumption is evident at this point: I am assuming that there will be no "cure" for aging, at least not in our lifetimes, or that if there is a cure, it will be very expensive. There will not, I assume, be the equivalent of the Salk polio vaccine for aging.

¹⁷ Norman Daniels, *Just Health Care* Cambridge University Press, 1985. Norman Daniels, *Am I My Parents' Keeper?* Oxford University Press, 1988. Norman Daniels, *Setting Limits Fairly: Learning to Share Resources for Health*, 2nd ed. Oxford University Press, 2008.

¹⁸ Daniel Callahan, *The Troubled Dream of Life* Simon & Schuster, 1993. Daniel Callahan, *Setting Limits: Medical Goals in an Aging Society* Georgetown University Press, 1995.

¹⁹ To some extent, outsourcing healthcare to families is already happening in Europe, too. Again, using the U.K. as our example: "The research by the London School of Economics and Institute of Psychiatry said that caring for one person with late-onset dementia costs an average of 25,472 pounds per year. At the present time, the bulk of this cost is met by the person with dementia and their families." <http://www.disabled-world.com/health/aging/dementia/uk-dementia-statistics.php#ixzz1OygMekHW>. Accessed 25 August 2011.